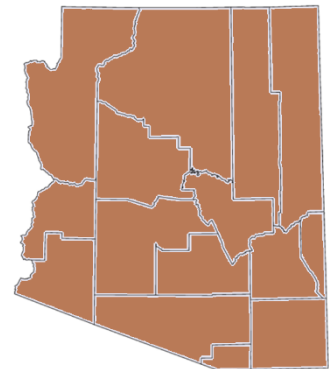


ARIZONA HUMAN RIGHTS COMMITTEE

Division of Developmental Disabilities

2017 ANNUAL REPORT



Arizona Department of Economic Security

District West Human Rights Committee 2017 Annual Report Maricopa County (West Area)

INTRODUCTION AND BACKGROUND:

Human Rights Committees, supported by the Arizona Department of Economic Security (DES), were established into law under A.R.S. 41-3801 and functions as an independent advisory and oversight committee to the Division of Developmental Disabilities (DDD). Human Rights Committees (HRC) were established to promote and protect the rights of members with developmental disabilities who receive services from the Division of Developmental Disabilities.

District West HRC is located on the west side of Maricopa County and extends south including portions of the Gila River Indian Reservation, to North Phoenix, and West to the border of Arizona. In 2017 District West served over 7,000 members.

District West HRC is the fastest growing district in membership for the DES and DDD. The monthly meetings are held at the Peoria DES office in Peoria Arizona. The committee meets on the fourth Tuesday of month for approximately two hours.

RESPONSIBILITIES AND DUTIES OF THE HUMAN RIGHTS COMMITTEES:

The Human Rights Committees (HRC) are made up of dedicated volunteers, who donate their time to serve the members within their districts. The HRC operates under the Open Meeting Laws of Arizona, and follows specific HRC Guidelines created by their district. The District West Committee meets approximately ten times per year.

The committee provides independent oversight, review, research and also makes recommendations to the Department of Developmental Disabilities. The committee reviews incidents of Abuse and Neglect, Emergency Measures, Human Rights Violations and Death. The committee members also review Behavior Plans (BPs) and make recommendations for change.

DISTRICT WEST HUMAN RIGHTS COMMITTEE MEMBERSHIP:

The District West Human Rights Committee (HRC) is comprised of dedicated community members including parents, family members, professionals, and paraprofessionals who volunteer their time and knowledge to advocate for DDD members.

Current members for the 2017/2018 year are: Diedra Freedman (De) (Chairperson), Pat Thundercloud (Vice Chairperson), Bernadine Henderson, Jennifer McNeill, Michelle Lagas and Brad Doyle. All of the current members were appointed

since November of 2017 with the exception of Pat Thundercloud who was a member throughout the 2017 year.

The resignations of the previous Chairperson and 4 other members occurred after May 2017. Recruitment efforts from June through October netted 5 new members with two appointments in November 2017, two appointments in December 2017 and one appointment in January of 2018. Unfortunately there weren't enough members to create a quorum until November 2017, so there weren't any meetings held from June to October 2017.

DISTRICT WEST HUMAN RIGHTS COMMITTEE VOLUNTEER HOURS:

The District West HRC volunteered 245 hours of their time in 2017

2017 ACTIVITIES

INCIDENT REPORTS

District West HRC reviewed a total of 539 Incident Reports (IRs) for over its 7,000 members. From June to November of 2017, District West HRC did not hold meetings due to lack of membership and not meeting the required quorum for meetings. This is why the number of reviewed IRs is so small. The HRC was unable to meet to review any IRs during that time period.

In 2018 the District West HRC will begin to receive every type of Incident Report, including Physical Abuse, Sexual Abuse and Other Abuse, Neglect, Accidental Injury, Missing Clients, Emergency Measures, Human Rights Violations, Medication Errors, Death, Suicide, Hospitalization, Incarcerations, Theft and Property Destruction.

Behavior Plans

District West HRC reviewed a total of 38 Behavior Plans while in committee. Once again for lack of membership there weren't more Behavior Plans reviewed.

Pat Thundercloud continues to go to the Program Review Committee (PRC) meetings and had volunteered 188 hours as a HRC member in 2017. She is consistently involved in attending the PRC meetings and is an advocate for the process.

District North (Flagstaff)
Human Rights Committee
2017 Annual Report
Coconino, Apache, and Navajo Counties

1. The HRC repeatedly reviews Behavior Treatment Plans and Incident Reports which address instances of sexual assault (both of victims and perpetrators), inappropriate touching, disrobing or exposure in public, and public masturbation. As sexuality is a normal human expression it is necessary that DDD members are allowed to express themselves in an appropriate manner. A comprehensive Sex Ed program such as that used in Maine (digitalcommons.usm.maine.edu) is necessary.
2. There continues to be a need for guardians to protect individuals who have severe cognitive disability.
3. Dental care is lacking for DDD members and extraction is most often the choice of treatment after years of neglect. Lack of appropriate dental care is a health threat and the cause of chronic pain in those unable to communicate. We urge full funding of dental care.
4. Housing support for high functioning individuals who need assistance for physical care but are otherwise independent is necessary. These individuals are often housed with severely behavioral individuals or in individual homes where a normal interaction with the community is difficult to obtain. We are aware of support for particular (higher functioning autism spectrum individuals) groups and look forward to the DDD committing to the same attention to high functioning individuals with physical disabilities.
5. Once again the HRC reiterates the need for a Step-Down Facility for DDD members who have been in mental health facilities, in hospital, or have undergone medication changes to allow transition time with supervision.
6. Providers are ever more frequently utilizing law enforcement for behaviors addressed in the BTP rather than following the interventions described in the BTP. Involving law enforcement in this situation violates both the intention of the BTP and is an inappropriate use of public resources for the benefit of a private entity.
7. The suppression of minimum wage and underfunding of DDD providers by the State of Arizona has caused difficulty of hiring and retaining appropriate workers for group homes and has caused providers to flee Flagstaff. Increase of statewide minimum wage and increased payment for providers

are necessary to the safety and proper supervision, protection, and improvement of quality of life for all members.

District South (Tucson)
Human Rights Committee
2017 Annual Report
Pima Cochise, Graham, Greenlee, and Santa Cruz Counties
and Yuma Counties

INTRODUCTION AND BACKGROUND

It is a pleasure to submit our 2017 Annual Report for the Human Rights Committee (HRC) in Tucson with support to Sierra Vista and Yuma. Because there was no Human Rights committee operating in Yuma and the new Sierra Vista committee was in the process of rebuilding during this period, the Tucson committee reviewed all Incident Reports from those areas as well.

Human Rights Committees were established under ARS 41-3801 and function as independent advisory and oversight bodies across the State.

RESPONSIBILITIES OF THE HUMAN RIGHTS COMMITTEE

The Human Rights Committee of dedicated volunteers, in addition to providing independent oversight and review and making recommendations, functions under the Open Meeting Law and follows District-specific Bylaws. The committee includes professionals and paraprofessionals, as well as interested parties.

SPECIFIC CHALLENGES

This calendar year brought several challenges to the basic functioning of the Tucson Human Rights Committee. As mentioned in previous year's reports, Behavior Treatment Plans continue to be inconsistent in structure and order and are difficult to read. The Tucson committee feels that the lack of consistent quality and general unreadability of the BTPs represent real violations of human rights for members due to the inability of care givers and service providers to understand the plans. We would like to see a more consistent format for BTPs and the use of wording that is easily understood by all service providers.

The committee in Tucson has enjoyed tremendous growth over this past year, due to robust recruitment effort both locally and statewide. In particular, the new local Volunteer Coordinator, Donna-Marie Terranova has been invaluable in the recruitment of highly qualified individuals for the committee who have wide-ranging experience in dealing with individuals with developmental disabilities. This wealth of experience should prove to be an asset to the committee moving forward. New HRC liaison, Taylor Pike, has aided the new member process by coordinating applications and following the applications through the system, greatly helping to improve the efficiency of the new member process. As of the end of December with the resignation of one existing member and the addition of eight new members, we had a total of ten official members.

The committee continues to struggle with redaction issues in both Incident Reports and Behavior Treatment Plans. Issues include incomplete redaction, too much information redacted, and inconsistency in levels of redaction. All of the above issues interfere with the committee's ability to track the incidents and individuals involved, which renders the committee nearly useless in its limited ability to protect the rights of members. The committee is seeing more progress in developing communication with both Child and Adult Protection agencies and with local law enforcement. It is hoped that the communication processes will continue to develop to share necessary information regarding investigations into Incidents so that the committee can do a better job of protecting members.

The Tucson HRC moved its meeting location to the downtown office located in the Department of Economic Security building located at 400 W. Congress Street. This facility can accommodate our growing group very well. Liaison Taylor Pike has taken over the duties of reserving our meeting rooms, notifying members of upcoming events, obtaining the Incident Reports and Behavior Treatment Plans for committee review, recording and drafting meeting minutes, and numerous other tasks required to support the committee. She has greatly improved the functioning of the committee and has not only provided guidelines to keep the committee in compliance with meeting laws, but has actively advocated within the Division to help the committee to function better and more efficiently. This committee is deeply grateful for the addition of Ms. Pike in the administrative capacity and we value her dedication to the goal of helping the committee live up to the potential and vision in the protection of human rights for the population served by the Division.

Throughout 2017 the committee addressed questions regarding Incidents to Quality Assurance. These questions were handled by Pauline Selmer, who was thorough in explaining processes and results of Quality Assurance fact finding. This system efficiently works to inform the committee of issues resolved.

The Tucson committee is working to find efficient and effective ways to protect the rights of individuals with developmental disabilities through ever-evolving procedures and systems. We continue to work with the HERO team to develop new channels of inter-agency communications so that we can do our job more effectively. We are optimistic that we will be able to better fulfill our purpose as we continue to work with the State and community agencies to serve the members here in District South.

MEMBERSHIP

The Tucson Committee

The Tucson committee membership grew throughout the year.
The members include:

Lynda Stites (Chair)
Stacy Santos (Resigned)
Genevieve Valenzuela
Cynthia Fielding
Lynne Tomasa

Francelia Garcia
Tyler DeMers
Jessica Richards
Cathy Curtin
Christine Small
Bill Burnett
DES Staff supporting the committee include:
Taylor Pike, Human Rights Committee Liaison
Department of Economic Security
Division of Developmental Disabilities

Richard Kautz, CPM
Advocacy and Special Projects Manager
Department of Economic Security
Division of Developmental Disabilities

The Sierra Vista Committee
RECRUITMENT AND TRAINING

Donna-Marie Terranova, new Volunteer Coordinator for District South, has been actively recruiting new members for the Sierra Vista region.

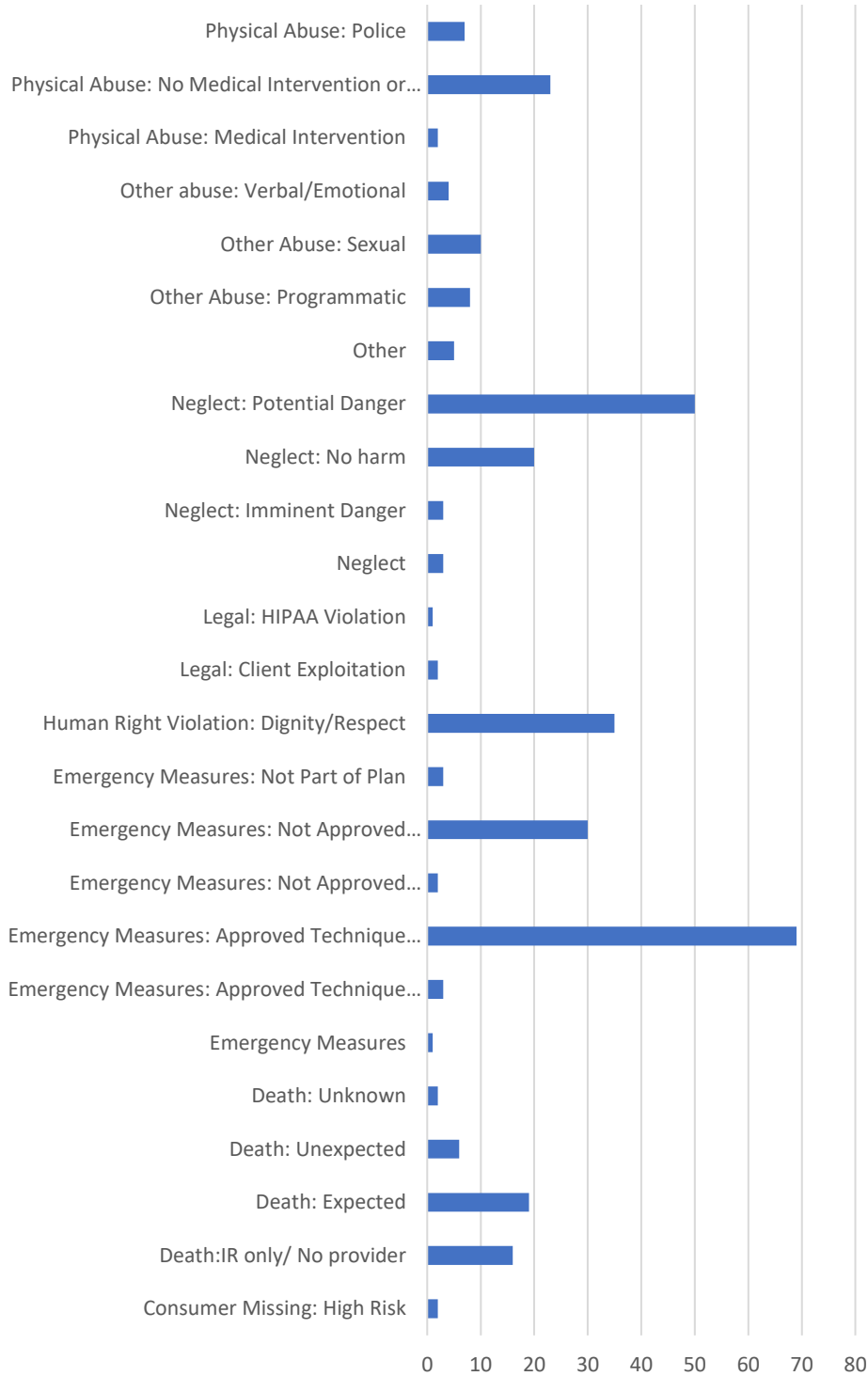
ORGANIZATIONAL STRUCTURE

The HRC's are groups of volunteers with DDD staff offering clerical support and providing the committee with Incident Reports to review and Behavior Treatment Plans to approve.

STATISTICS

	IR's Reviewed	BTPs Reviewed	Meetings Held	Volunteer Hours
Tucson	326	158	8	195.75

District South Incidents Reviewed 2017



OTHER ACTIVITIES

The District South committee has maintained a tracking system of all Incident Reports reviewed to track trends and agencies over time. When the committee reviews Behavior Treatment Plans monthly, each member reviews several plans at home and then returns the approved or not-approved disposition form to Liaison Taylor Pike.

This concludes the annual report of the Human Rights Committee, District South.

Respectfully submitted,

Lynda Stites
District South Human Rights Committee Chairperson

District Central Human Rights Committee 2017 Annual Report Maricopa County

HRC Committee Membership of 2017

Karen Van Epps, Chairperson; Family Member/Advocate
Carol McNulty, Vice-Chairperson; Family Member/Advocate
Eva Hamant; Parent/Advocate
Mandy Harman; Receives DDD Supports
Linda Mecham; Parent/Advocate/Educator
Andrea Potosky; Parent
Debbie Stapley; Parent
Lisa Witt; School Psychologist/Family Member
Eduarda Yates; Parent

Article IX

During the 2017 calendar year the HRC has noted several concerns in relation to Article 9. It was discovered that the Division created a committee to rewrite article IX. Specifically, the rewrite consisted of trying to take out the need for a behavior plan if someone is on psychotropic medications. This was a particular concern as the changes were being made in private. It was not until the Article IX rewrite was brought to light that providers and the public were involved. The HRC recommends that policy changes that involve the HRC's statutory authority be sent to the HRC before they take effect for comment.

Behavior Treatment Plans

The Division needs to adhere to the policy of Article 9 as it pertains to members required to be present during the Program Review Committee (PRC). A behavior specialist should always be present at each PRC. There is also a lack of vendors and support coordinators available for the PRC meetings. HRC recommends that the vendors should be required by contract to attend and participate in the PRC process. HRC recommends that the vendor send staff that work with the member. The committee would also like to see an HRC member added to R6-6-903(E), which constitutes the composition of the PRC.

If a member is on probation or a court ordered restriction, the HRC recommends that information be included in the Behavior Treatment Plan (BTP) and the Individual Service Plan (ISP).

Behavior Plans Reviewed

Jan	82
Feb	62
Mar	70
Apr	54
May	70
June	52
July	53
Aug	41
Sept	32
Oct	68
Nov	62
<u>Dec</u>	52
Total =	698

Listed are the District Central 2017 monthly PRC Plans that were received and processed: State OPS – Sedation and Dental Approvals (HRC) 23 + 698 = Total process = 721

Incident Reporting

HRC recommends the Division to have their own investigators instead of relying on the Department of Child Safety (DCS) and Adult Protective Services (APS). The HRC is concerned that antecedents are not included on the Incident Reports (IRs). The HRC recommends that IRs include precursors and antecedents.

Incident Reports Reviewed

The DC HRC reviewed a total of 1,388 incidents that occurred in 2017. 355 of those incidents were open incidents with the remaining 1033 being closed incidents.

Jan	142
Feb	60
Mar	117
Apr	113
May	195
June	248
July	115
Aug	70
Sept	129
Oct	-
Nov	117
<u>Dec</u>	82
Total =	1388

Pilot Project

During late 2017, the HRC acquired copies of the Cholla Pilot Project which intends to replace the current ISP planning document. Upon review of the document several concerns were noted. The Pilot Project documents questions do not properly address an individual's needs by asking questions that cannot be properly addressed. Such questions could lead to behavioral incidents when people cannot get what they want. The document also leaves out important topics related to communication. For example, a person who is non-verbal would not be able to properly address several areas of the Pilot Project document. The committee is also concerned that the Pilot project document is extensively longer than the current ISP planning document. This addition of paperwork is a step away from a stance of paperwork reduction plans. The HRC currently recommends that the Pilot Project be ended due to the current ISP document meeting members' needs.

Bed Bugs

The HRC has recognized that DDD currently has no policy for bed bugs. When an individual has come into contact with bed bugs, providers and family have no answers to address the concern. There is an impact on individuals who are sent home from services due to bed bugs. The HRC recommends that DDD develop a policy that

addresses how provider agencies and families should approach the concern of bed bugs. In addition, such a policy should address how bed bugs should be treated.

Nursing Homes

The HRC is concerned that DDD members are placed in nursing homes and not be given alternative options, such as intermediate care facilities (ICF) or medical group homes. Nursing homes are not equipped to meet the unique needs of DDD members. In addition, members do not receive DDD services while in a nursing home.

Skilled Nursing Facilities (SNF) should not be a long-term option for DDD members. There are valid reasons for a person to go to a SNF. However, incidents exist where people have been in a SNF long-term. People in nursing homes are given PRN medications and psychotropic medications. According to Article 9, if the Division is paying for it a behavior plan must be developed. The issue is that behavior plans are not being developed when a member is in a SNF and when a member is given PRN medications or psychotropic medications. The HRC recommends that individuals are given alternative options to a SNF. The HRC recommends that the Division ensures individuals given PRN medications and psychotropic medications in a SNF, follow Article 9 requirement's to have a Behavior Plan developed.

Client Billing/Funds

The HRC is concerned that members, for whom DDD is the payee, are going over two thousand dollars. In the instance a member goes over two thousand dollars they lose their ALTCS eligibility. The HRC is concerned that spend-down plans may need to be easier. In addition, there is concern as to support coordinators deeming a member's request for spending frivolous. The HRC recommends that the Division perform spend downs in a timely manner to ensure members do not lose their ALTCS eligibility.

Therapist Shortage

The HRC has recognized that there is a shortage of therapists. It has been reported to the HRC that therapists are not easily obtained when needed. Therapists are known to not report to the rural areas. The committee feels there is a loop hole between the DDD member, budget approvals, and the Medicaid program. The committee recommends the Division to work more closely with contractors to alleviate this concern so services can be provided to those in need of therapy services.

Lack of Support Coordinators

The HRC has a reoccurring problem in District Central in relation to low staff members and high caseloads. DC offices have been noted to be understaffed with support coordinators. This leaves DC support coordinators with higher caseloads. These higher caseloads could further lead to more turnover thus creating concerns with staff not addressing the needs of members and families. The HRC recommends that the Division retain staff in DC offices to ensure caseloads lower.

Minimum Wage Increase

The Human Rights Committee (HRC) has for years and currently provides independent oversight to Division of Developmental Disabilities (DDD). With the passage of Proposition 206 the committee has witnessed several concerns that are affecting the well-being of some of Arizona's most vulnerable individuals. Under Proposition 206, the Fair Wages and Healthy Families Act, Arizona minimum wage increased to \$10 per hour in 2017 and will increase \$12 per hour in 2020.

Due to the Arizona minimum wage increase, those who provide services for DDD members are finding it difficult to retain competent employees. Before the wage increase, service providers were able to pay staff with more competitive wages above minimum wage. However, due to the rise in minimum wage, prospective employees are seeking work elsewhere leaving our members in need of qualified staff. Most of the members served by DDD require twenty four hour assistance related to their daily living skills, behavioral health concerns, and in some instances high medical needs. Addressing these needs often require well experienced and well trained staff. The duties of staff while serving DD members are often difficult and require critical skills. Staff act as a coach, teacher, and mentor to facilitate the development of specific skills and behaviors to promote self-determination and independence.

The nature of this work is often difficult, prospective and current employees who provide services to our members are seeking employment in fields outside of caregiving. Often time's vendors of the services are unable to fill positions or will fill the position with unskilled workers which exacerbate our concerns. Having unskilled staff to care for individuals with a developmental disability can lead to increased incidents of abuse and neglect. These incidents in turn compound when the employee is released from their duties and the member is left without staff to assist them. This affects members in a variety of settings. 87% of the members live in their own homes where attendant care and respite services are provided. Losing these service providers would mean a great portion of our members would not be able to remain home in a safe and clean environment.

HUMAN RIGHTS COMMITTEE DISTRICT EAST 2017 ANNUAL REPORT

Division of Developmental Disabilities

**Prepared by Suzanne (Kensington) Hessman Chairperson
on behalf of the Human Rights Committee District East**

Human Rights Committee Function

Human Rights Committees (HRCs) are required by ARS 41-3801 and 41-3804 and function as an independent advisory and oversight committee for members being served by the Arizona Division of Developmental Disabilities. District East serves the southeastern portion of Maricopa County, southern portion of Gila County and all of Pinal County, including the Arizona Training Program at Coolidge.

Each committee shall provide independent oversight to:

- Ensure that the rights of clients are protected.
- Review incidents of possible abuse, neglect or denial of a client's rights.
- Make recommendations to the appropriate department director and the legislature regarding laws, rules, policies, procedures and practices to ensure the protection of the rights of clients receiving behavioral health and developmental disability services.
- Each committee shall issue an annual report of its activities and recommendations for changes to the director of the appropriate department, the president of the senate, the speaker of the house of representatives, the chairpersons of the senate health and human services committee and the house of representatives' health committee, or their successor committees.

Our primary efforts have been focused on reviewing Incident Reports given to us by DDD Quality Assurance and Behavior Treatment Plans submitted to DDD, that have been approved by Program Review Committee for DDD, for individuals who live in a DDD residential setting and are taking any medication(s) that assist in behavior modification. In addition, we have advocated and counseled with individuals and their families.

Reports Requested to Review

We have requested to review the following reports which have not been delivered to our committee:

- Residential monitoring compliance reports and summaries of homes monitored in the area along with corrective action plans
- Reports of special investigations received by the Division
- Provider investigations, subsequent analysis of report findings, and corrective action plans
- Data and trend analysis compiled by the Division's Quality Assurance Program
- Incident Reports for every category

Membership

Suzanne (Kensington) Hessman – Chairperson – Parent/Advocate, Realtor

Jennifer Huot – Vice Chairperson – Special Education Teacher

Gina Johnson – Parent/Advocate, Founder of Sharing Down Syndrome

Leon Igras – Parent/ASU Safety Director

Sheri Reed – Parent/Special Education Teacher, PhD

Tammy Leeper – Parents/Nutritionist

Mindee Stevenson – Parent

Sarah McGovern – Parent

Cathy Walen – Guardian, Attorney – Public Defender in Mental Health Court

Jill Wilson – Advocate, Parent

Paul Sadler – Parent

Joy Smith – Parent

Per ARS 41-3801 our committee is to be comprised of at least seven and no more than fifteen members with members having expertise in the following areas: psychology, law, medicine, education, special education, social work and at least two parents of children who receive services from DDD.

2017 was a good year for recruitment as we had 6 new members join and 2 members take hiatus. The new members all came from the DDD newsletter outreach efforts. Training is an ongoing issue as there is no set curriculum or standard for training new members. This needs to be standardized across the state. This could be accomplished with recorded webinars on each topic area that new members can watch at their own pace.

Our committee is made up of individuals who are employed full time, primarily parents who have children receiving a variety of services from DDD and Behavioral Health. As such, we all bring insight from our experiences with the Division and the agencies providing services. Our diverse insight allows our committee to openly discuss differing points of view to come to a collective decision on matters before us. Dedicating the time necessary to participate on the committee has been a strain at times on our members as they also have had to handle issues experienced by their children served by the Division; however, they chose to serve in order to make a difference.

DDD Staff

2017 was another year with lots of changes for the division. Dr. Laura Love retired as Assistant Director and Maureen Casey took over that position. District East had been without a District Program Manager from January through March, when Sam Rogers took over that position, however she retired by the end of the year. In October 2016, the PRC Chairperson position was filled after that position had been vacant for over a year. However, the new PRC Chairperson refused to forward on our BTP recommendations to agency providers, which rendered our advocacy for our members as moot. We did meet on a statewide level as a "Work Group" to discuss processes and procedures to help DDD help us to do what we are legislatively required to do. Three HRC Liaisons were hired for the entire state. Some processes agreed to by DDD were implemented and others not. It has been a work in progress.

In February we were invited to a stakeholder's meeting with Senator Nancy Barto to discuss HRC functional issues to address in a HRC bill. Dr. Laura Love was at this meeting. Senator Barto asked Dr. Love why the HRCs were not getting the requested items and support needed to do their jobs.

In order to streamline administrative staff duties, as well as help our committee operate in the most efficient way possible, we have repeatedly requested a solution of some web-based distribution. We haven't received any approval or support from DDD in those efforts. We created our own Dropbox where we have references, resources, training, agendas, past minutes and time sheets available for easy access. We are currently working on collaboration and communication regarding IRs and BTPs through Dropbox. What we are requesting is that BTPs and IRs to be distributed to us through this manner. This would give us the ability to refer back to previously reviewed BTPs to ensure requested changes were made and previously reviewed IRs to track ongoing issues with individuals or agencies. This would eliminate the need for administrative staff to redact and produce copies, reduce paper waste and eliminate the need to collect and shred documents.

Program Review Committees

PRCs are not meeting the mandated number and makeup of members. Many times BTPs are approved by the PRC Chair and one or two other members. This does not provide the adequate oversight to ensure that these plans are addressing our members behaviors. Many of these plans approved are being written by an outside agency with little to no information on the member they are writing these plans for. We find plans that are cut and pasted and sometimes don't even have the right member's name on the plan. Behavior Treatment Plans are important in protecting our member's rights, otherwise we are essentially just medicating them and not teaching a replacement behavior. We have also become aware that legal guardians are not being notified of when the PRC will be reviewing their member's BTP. Plans are being created with out input from legal guardians and other team members.

Incident Reporting Format

There has been lots of confusion and inconsistency on the issue of redaction. Every couple of months the information being redacted changes. The issue of redacting reports hampers our ability to provide the oversight the law requires.

The committee found that the current IRs do not provide enough information to form an opinion on what occurred. We need to have statistical and expanded information about these agencies, staff and clients to get the bigger picture. What was the antecedent? What was the precursor? Is there a guardian? Where do they reside? Is there a BTP in place? Is it working? Number of incidences regarding this client in the last 90 days? This information would allow us to make more informed recommendations to improve the quality of life. We also would like more information on specific actions that were taken regarding the IRs to protect our members and prevent further problems. Currently our reports show substantiated or unsubstantiated by APS or DCS but no report from those agencies. This leaves us wondering as to the depth of the investigation as in most cases the reports show unsubstantiated.

Direct Care Staff

Our committee found that the quality of life of our individuals is severely impacted by the lack of quality direct care staff, poor training of that staff and low wages. We read wonderfully written ISPs and BTPs only to find that they are not being read by agency providers and therefore not being followed. There is substantial failure on the part of many providers to properly train direct care staff. Providers complain that there is a shortage of quality workers.

The passing of the minimum wage law caused many issues for providers. Many smaller providers were not able to keep their businesses open. In some cases, larger agencies picked up the slack and in many more, members were left with no services.

Standardized mandatory behavioral training for direct care staff who care for clients with extensive behavioral needs require ongoing mandatory continuing education to be provided by Behavioral Health Specialists. This would help to minimize use of emergency measures, decrease escalation of behaviors resulting in verbal and physical aggression, property damage, self-abuse, crisis and police involvement. Workers having specialized training will be able to better implement behavioral treatment plans and therefore experience less behavioral issues from the members. This would create better employee retention and reduce training costs for agencies.

AHCCCS implemented Direct Care Working training and testing programs for workers providing in-home care services (attendant care, personal care and homemaker services). This program does not apply to licensed settings. This program would be a good start, however not comprehensive enough for working with members with extensive behavioral needs.

There is an overall theme seen both in BTPs and IRs regarding members wanting to be respected by not being rushed, not being spoken to like a child, not having power struggles with staff, saying no and not giving reasons behind the no, not being sincere, staff not being aware of tone of voice and body language, members not being aware of who is working with them in advance, and members not being aware and informed of their schedule in advance.

We were currently tracking individuals who are named as the perpetrator in an incident report but were not found to have been substantiated by APS despite evidence to the contrary. However, DDD has decided to redact direct care provider's names from the Incident Reports. We believe there needs to be a list maintained by the division to prevent direct care providers from jumping from agency to agency.

Behavior Treatment Plans

Behavior Treatment Plans should be in a consistent format like Individual Service Plans created by Support Coordinators. This would allow ease of reading for Support Coordinators, Providers, Direct Care Staff, PRC and HRC. It would ensure that all necessary information be in the plan. It would provide consistency from member to member, agency to agency and district to district. This would prevent agencies from seeking out presenting their plan to the district they feel is easiest to get approval from, as well as help those agencies struggling with creating appropriate plans.

It is hard for our committee to make a determination as to whether an individual is on an appropriate amount of medication or is over medicated. Our committee requests that an expert in this field be provided to review to ensure members are not over medicated.

Our committee requests that it be provided with a behavioral consultant to provide expertise into the effectiveness of the plans that are presented.

Currently DDD has no tracking system to ensure that provider agencies have current BTPs in place for members that are required to have them. There were many plans that were submitted that were way overdue or about to become due again. This is a huge human rights violation as agencies are not properly handling members' behaviors. They hire staff that babysit, rather than follow ISP outcomes and run BTP outcomes. Members' behaviors escalate out of control resulting in provider agencies calling crisis and/or the police and press charges against our members. There is a systemic problem of agencies having a policy of calling the police on our members for behaviors, rather than having appropriately trained staff in place to manage the behaviors. During training, all staff must follow Crisis Prevention Intervention strategies. We would like to see the Division track police involvement to track and trend and then take action against agencies that have these policies in place.

Currently when an AIMS report shows that a member is having negative side effects from the behavior modifying medication there is no follow up or action taken by the Division to protect the rights of the members.

Police Involvement

Many times when agencies call “crisis” they are told to call the police. The police do not have the appropriate training to deal with our members. The police, as well as the jails and courts are not the appropriate place for our members. Involving the police can result in tragedy such as death, which was experienced in our district last year.

The jails treat them as a typical criminal and don’t understand their unique specialized needs. Members have been denied their medications while in jail resulting in further behavioral and medical issues. The experience with the police, jail and the judicial system causes an escalation of behaviors and/or PTSD. Policy changes need to be instituted to prevent these things from happening. These issues are directly in opposition to laws and policies in place to ensure our members human rights.

Provider Accountability and Provider Report Cards

DDD needs to provide more transparency with members, their families and guardians. When incident reports are made regarding their member, families deserve to know the outcome of the investigation and any course of action taken by DDD or the agency.

Families should be provided a copy of the contract that an agency has with DDD when caring for their member. This provides clarity of what is being expected for their compensation. There should also be transparency as to the amount of compensation received for services rendered.

Families have the right to know who is working with the member, what their background results are, agency policy for drug tests, and violation consequences/follow up when incidents occur.

Many members and their families are afraid to report agencies and direct care staff for the very real fear of retaliation against the member in their care.

Cameras should be allowed in day programs and residential settings if requested by guardian. We have seen all too often DCS and APS come back from their investigations with “unsubstantiated” because it is a he said, she said situation. Cameras would eliminate these ambiguities and provide protection against false allegations for providers. We find that more often than not our members are not believed and are blamed for circumstances that could very easily be abuse. In addition, many times direct care workers are removed from working with vulnerable members for long periods of time while awaiting the results of the investigation.

A report card system needs to be in place so that families can make educated and informed decisions as to the providers that they want to work with. The report card system should utilize feedback from QA, SC and families/guardians and be available on DDD's website for public access. This has become a common practice for professionals like attorneys, doctors, realtors, general contractors etc. and should be no different for providers. Questions such as: How long have they been in business? Number and category of incidents? Were they corrected? Systems in place? How many homes? Total number of clients? Staff ratio? Staff turnover? How often are clients leaving or provider is releasing them? Would be beneficial information.

Agencies experiencing issues should not be given more members to service when they are failing to provide quality of care to the members that they are servicing. There seems to be a lack of accountability of enforcing provider's contracts to the detriment of our members.

Health Issues

In October 2016 \$1000 allowance was implemented for dental care for our members over the age of 21. Many members are having teeth pulled resulting in additional health problems, such as digestive issues and gum cancer. Providers are not providing adequate daily dental hygiene to the members.

Diabetes, obesity, digestive and other health issues are often times a direct result of group homes not providing nutritional meals for our members. Direct care staff eat fast food and drink sodas in front of the members which not only provides a poor example but also results in behaviors due to members wanting the fast food and sodas as well. This year we have addressed issues where group homes are refusing to provide nutritionally required healthy meals to members in the homes.

We read a few incident reports regarding a group home or DTA van arriving at their destination, only to later discover a member was left in the van by themselves. Incidents such as this can lead to neglect, medical issues or death. It is extremely important that group homes and DTAs have systems in place to ensure that this never happens.

Human Rights

Providers are refusing to take and support members in their religious activities because it differs from their own religious beliefs. It is important that agencies train and enforce direct care workers to understand that their job is to support the member in the activities they wish to participate in.

Agencies are not respecting cultural sensitivity of our members. Members are forced to have direct care staff that are very different from the members causing the members to be uncomfortable and not get their needs met. These cultural differences were seen in having thick accents which caused problems in communication, religious preferences not being respected, meal preparation of an

origin not comfortable to member, staff not knowing how to brush hair different from theirs and staff not comfortable with member's pets due to cultural differences. Our members have the right to have staff that they are most comfortable with.

Adequate Residential Settings

There is a lack of agencies able and willing to service members with high behavioral needs. This results in members living for long periods of time in unstable and/or potentially harmful situations where they are not happy. This results in decomposition of the member and a worsening of behaviors. Members have the right to be in a happy stable home.

Behavioral Health Hospitals

There are no behavioral health hospitals in Arizona prepared to appropriately meet the needs of our members when psychiatric hospitalization is required due to medication changes that need to take place in an inpatient setting. They are thrown in with mentally ill, criminals and drug addicts. This is true in outpatient facilities such as UPC and SMI clinics as well. There needs to be specialization for our members that are set apart as their needs are very different due to the developmental issues and would be more effectively managed with specialization. Furthermore, the division between DDD and Regional Behavioral Health causes the dually diagnosed members to navigate an extremely confusing system which has either side pointing fingers at who is supposed to be providing services. Behavioral health needs to be under one umbrella for our members. This collaboration of cooperative care should be a high priority.

ARC Reports

During 2016 The ARC's contract changed from monitoring the quality of life for a sample of the entire DDD residential population to only covering the members from Griswold v. Riley settlement. There are only 57 individuals still living that are covered by the settlement. The ARC is paid \$50,000 per year for this contract. Although we believe that the ARC wasn't providing adequate monitoring and reports, now the rest of members now are not being looked at separately. We only received 8 reports that all look the same and no parent or guardian questionnaire information.

Placement	All Other	District East	Statewide
ADH	1012	271	1283
Adult Therapeutic Foster	1	0	1
Assisted Living	5	1	6
Child Developmental	140	74	214
Group Home	2571	447	3018
Home	27299	8654	35953
ICF	31	7	38
ICR/MR	116	6	122
Level 2 & 3 BHC	3	2	5
ATPC	0	83	83
Totals	31180	9462	40642

BTP Reviewed	IR Reviewed	Meetings Held	Volunteer Hours	Valuation of Donated Hours
259	791	10	583	\$14,575

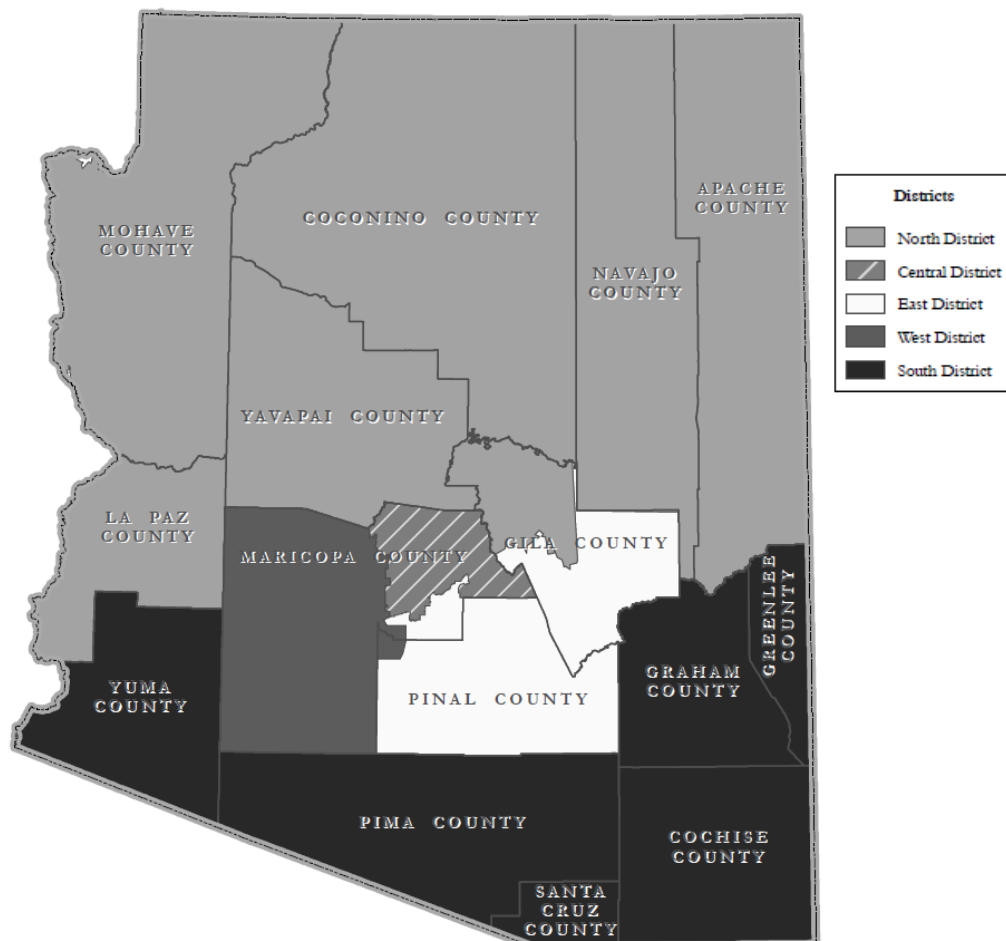
These issues and recommendations have been previously discussed with DDD management via phone, email, District East meetings, statewide meetings, and individual meetings.

This report is a compilation of District East meetings, statewide meetings, review of Behavior Treatment Plans for DE, review of Incident Reports for DE, meetings with families, providers and DDD employees and personal experiences of our committee members during 2017.

Suzanne (Kensington) Hessman, Chairperson

Geographical Composition by County and Chairperson

District Central:	Maricopa County (Central Area) Chairperson (Phoenix): Karen Van Epps
District East:	Maricopa (East Area), Gila, and Pinal Counties Chairperson (Mesa): Suzanne Kensington
District West:	Maricopa County (West Area) Chairperson: Mona Zucker
District South:	Pima, Cochise, Graham, Greenlee, and Santa Cruz Counties and Yuma Counties Chairperson (Tucson): Lynda Stites Chairperson (Sierra Vista): Mary Haynes (Interim)
District North:	Coconino, Apache, and Navajo Counties Chairperson (Flagstaff): Cynthia McKinnon Yavapai, Gila (Northern Area), Mohave, and La Paz Counties Chairperson (Prescott): Vacant



Human Rights Committees

Human Rights Committees (HRC), also known as Committee, are required by A.R.S. §41-3801 and A.R.S. §41-3804 to act as an independent advisory and oversight for the Division of Developmental Disabilities (DDD) and the people they serve. The Human Rights Committee ensures the rights of clients are protected by reviewing incidents of possible abuse, neglect, and denial of rights. Each Committee meets at least quarterly each calendar year. However, Committees generally meet more frequently. The Committee is comprised of at least seven and not more than fifteen members. Members will have expertise in at least one of the following areas of psychology, law, medicine, education, special education, social work, criminal justice, and shall include at least two parents of children who receive services from the Division of Developmental Disabilities. Each District Committee also has a Chairperson attend the statewide HRC quarterly meetings to review and discuss individual issues and practices that may have statewide impact. The meetings also serve as a venue to improve communications among local Committees, identify statewide issues, recommend solutions to the identified concerns, and foster the discussion and resolution of issues between the Committees and the Division's Administration. The meetings afford the Chairpersons the opportunity to compare notes and help each other to improve their operations and to evaluate and plan for consistency in operations, thus elevating the level of awareness of human rights issues at the State level.

Human Rights Committee Annual Report

The Committee issues an annual report as noted in the Statute. Each Committee shall issue an annual report of its activities and recommendations for changes. The purpose HRC Committees pay particular attention to incidents they review to determine if there are any trends that need to be brought to the attention of the Assistant Director. The annual report goes to the DDD Assistant Director, the DES Director, the president of the senate, the speaker of the house of representatives and the Chairpersons of the senate health and human services Committee and the House of Representatives Health Committee, or their successor Committees.

Committee Responsibilities and Activities Performed

The significant function of the HRC is to review incidents of possible abuse, neglect, and denial of rights. Monthly, the HRC reviews all incident reports in their District from the previous month. The HRC evaluates the incident to determine if there is any human rights violations. The HRC can ask the Division to obtain further information for clarification. That information may result in recommendation for the Division and/or provider agency. HRCs receive incident reports from their District's quality management department. Based on a review of an Incident Report, the HRC may request Quality Assurance arrange an unannounced visit to a Division funded setting.

The Committees review Behavior Plans for individuals with developmental disabilities and make recommendations to Division staff when the Behavior Plan

interferes with individual rights for persons residing in State funded residential programs. The situation may or may not infringe on the individual's rights, but may nevertheless be at odds with the principles of self-determination, independence, or with issues related to least restrictive environment considerations. Subsequent discussions from this independent oversight and free flow of ideas allows for a better understanding of the complex interactions between Behavior Plans and individual rights. Upon review of a Behavior Plan, the Committee may make recommendations to the Program Review Committee (PRC) about any possible human rights violations. HRCs receive Behavior Plans from their District's Program Review Committee.

The Committees have a responsibility to review research conducted in the field of developmental disabilities for clients served by the Division. The Division will report the findings to the Human Rights Committees when they become available to the public.

Who are the Human Rights Committee Members?

HRCs are comprised of volunteers who donate time to the Division and each of the districts. Each district HRC has a chairperson, vice-chairperson, guidelines, and functions under the Open Meeting Law. Although many professionals and paraprofessionals serve on the HRCs, frequently HRCs include parents and family members of individuals that are currently receiving services. Many HRC members have served for several years and in some instances decades. This longevity provides the committees with continuity, stability, and expertise. The HRCs are supported by the Division's HRC Statewide Coordinator and District-specific administrative staff, who provide professional and clerical support for their operations.

Recruitment and Training

The year 2017 was an active year for recruitment of HRC committee members. The interested candidates have expressed their interest in-part to reading about the HRCs from the Human Rights Committees brochure, online volunteer postings, and presentations.

The search for qualified individuals who are willing to serve as HRC members has historically been a challenge. In 2017 the Sierra Vista HRC was reformed. In 2017 the Prescott HRC was disbanded.

HRC Chairpersons and Division staffs agree that recruitment efforts should extend to the entire community served by the Districts, in order to ensure a broader representation. Realizing the cultural and ethnic diversity of Arizona, Chairpersons continue to focus on recruiting HRC volunteers who represent a diverse base from every county they represent. The inclusion of new volunteers, some with no history of involvement with people with developmental disabilities, has brought diversity and a flow of new ideas to the HRCs.

Technical Assistance to Families, Staff and Providers

HRCs provide technical help, as needed, to families, providers, and Division staff. In most cases, HRCs help to address areas of conflict within the ISP Team or Behavior Plans that may interfere with the individual rights of Division members. The situation may not infringe upon members' rights, but it may conflict with the principle of self-determination, independence, or least restrictive environment. Subsequent discussions and the free flow of ideas allow for a better understanding of the complex interactions between behavior plans and individual rights.

Research in the Field of Developmental Disabilities

HRCs are required by law to review and preapprove (or reject) any plan for developmental disabilities field research concerning Division members. The Division reports any research findings to the HRCs, prior to making them available to the public. During 2017, no research proposals were presented.

The Role of the Human Rights Committees in the Divisions Quality Assurance Program

Data analysis is critical to a Quality Assurance Program, the primary goal of which is the improvement of conditions and outcomes for Division members and their families. In all Districts, HRCs and the Division's Quality Assurance Program work together on issues (e.g. abuse, neglect, and exploitation) concerning member rights.

Annually, District HRC Chairpersons and HRC Liaisons attend a meeting of the Statewide Quality Management Committee (SQMC) to present their annual report. The report includes an update on the District HRCs' activities and emerging issues/trends affecting their communities. The SQMC develops its annual goals, in part, to address the recommendations identified by the Statewide HRC Chairpersons' Annual Report, which is compiled from the individual annual reports of District HRCs.

HRC Statewide Coordinator

The HRC Statewide Coordinator and District staff will work with each of the HRC in their appropriate Districts and will continue to provide clerical support to each of the six (6) HRCs across the state. The Division has hired three HRC Liaisons for the purpose of providing clerical support to the HRCs statewide under the guidance and supervision of the Human Rights Statewide Coordinator.